

Autism Council Meeting
May 17, 2010
Draft Minutes

Council Members: Terri Enters, Rose Helms, Milana Millan, Pam Stoika, Michael Williams, Brad Thompson, Joan Ketterman, Glen Sallows, Vivian Hazell

Facilitator: Kristine Freundlich

DHS Staff: Julie Bryda, Bill Murray, Katie Sepnieski

I. Public Comment

- a. Council member Milana Millan spoke regarding the autism insurance mandate and the difficulty in finding a provider that is covered by her insurance. She can not find a provider within her rural area. She is now working with an out of network provider that has much experience working with older children with Aspergers. Other issues families are struggling with are high deductibles, travel time, and trying to help the parents find the services they need for their child.
- b. Jennifer Polick-Parent of child that was receiving RDI services through the CLTS Waiver until RDI was denied by the county. The family would like to appeal but has not been given the denial process.
- c. Steve Blyth-Parent of a child receiving RDI services. The child has made much progress over the last few years since beginning the program.
- d. Julie Bastler-two children with PDD-NOS are now receiving RDI services. The family struggled to find the appropriate treatment for the child including intensive in-home treatment. The family has worked with RDI for the past two years with significant improvement in social and peer engagement. This treatment is not covered by insurance.
- e. There were a few that wanted to testify via video but the speakers did not work so the council was unable to hear the video. The videos will be sent to the Council members. The written testimony was shared with the members.

II. Health Care Reform-Fredi Bove, Deputy Division Administrator

- a. The Federal Health Care reform is being monitored by the Department to determine how it will impact services and programs for children and families.
- b. The Bill supports Wisconsin's initiatives to expand community-based long-term care choices and rebalance the long term care system by providing enhanced federal matching funds to certain community-based long-term care services. The WI programs that will be impacted are:

- i. Money Follows the Person Program-The purpose is to relocate people from institutions into community settings. There are currently only 8 children in institutions
 - 1. WI has worked to keep children out of institutions but many of the short-term institutional stays may no longer be available to children even though may be appropriate.
- ii. Community First Choice Option-Allows the State to create a Medicaid-funded benefit with enhanced federal Medicaid funding that covers home and community-based attendant care to Medicaid members who are at the nursing home level of care. The services must be provided under a person-centered plan that is participant directed.
- iii. Family Care Partnership, which is a fully integrated long-term care managed care program for dual Medicaid-Medicare eligible adults, is delivered by four Medicare Advantage Special Needs Plans located in the state.
- iv. The Federal government will provide a total of \$10 million per year nationally for five years beginning October 2010 to fund and expand Aging and Disability Resource Centers
 - 1. WI may receive approximately \$180,000
- v. The CLASS Act provisions create a national voluntary public long term care insurance program for working adults ages 18 and over with automatic enrollment but opt out choice. No taxpayer funds are used in the program; it is entirely funded through enrollee premiums.
- vi. For Medicaid (Katie Beckett Program, BadgerCare, and CLTS Waivers) programs remain the same. The eligibility and services will not change. There may be additional funding from the Federal government in the future but again it will not change the programs or services being provided.
- vii. The Governor's office developed the Office of Health Care Reform. The office consists of the Department of Health Services and the Office of the Commissioner of Insurance.
- viii. Wisconsin developed a website to provide information to any interested parties www.healthcarereform.wisconsin.gov

III. Introduction of Council Members

IV. Informative Presentations

- a. Prior to the presentations the Council received information from both presenters regarding the treatment programs being implemented. The information sent were articles focusing on the evidence of the treatment.
- b. Presentation on RDI approaches-Dr Amy Leventhal and Deb Berrang from Dynamic Connections
 - i. The presentation focused on the treatment objectives of the program. The presenters shared information regarding:

1. Three studies; two were poster sessions and are not yet published. The third was a quasi-experimental design completed by the developer of RDI. As mentioned by the presenter there may be a potential for bias.
2. National Autism Council classifies RDI as an “emerging treatment.” Emerging treatment means there are not enough criteria to support or dispute the efficacy of the treatment.
3. The provider spends 2 to 4 hours per month with the parents to discuss concepts or they model the behavior with the child. The parents also implement the techniques in their everyday lives. There are video samples sent to the provider which are reviewed and then discussed with the family.
4. There were several videos that were presented which showed the improvement over time of the child being able to pay attention and gesture appropriately.
 - ii. Reviewed the Administrative Rules regarding evidence-based practice for Medicaid, Medicare and private insurance.
- c. Tamara Kasper, MS/CCC-SLP, BCBA presented on verbal behavior
 - i. Applied Behavior Analysis (ABA) intervention for autism is not a “one size fits all” approach consisting of a scripted set of programs or drills.
 - ii. At least 550 studies have been published showing the evidence of ABA. Most interventions for children with autism use behavioral analysis in their treatment model.
 1. A list of studies was provided in the power point that was presented.
 - iii. Verbal behavior as a form of ABA therapy has not been subject to research that demonstrates its effectiveness as a comprehensive intervention.
 - iv. The presenter emphasized the following conceptual frameworks of ABA
 1. Functional Assessment
 2. Motivative Operations
 3. Matching Theory
 4. Functional Communication Training
 - v. The presentation had video showing the different ABA techniques that are used as interventions.

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- V. Creative Approaches
 - a. Wendy Machalicek from UW-Madison presented on video-teleconferencing for children receiving autism services. Wendy is developing a pilot to determine if Rethink Autism is an effective means to implement treatment.

- b. The parent would be the interventionist after watching the video from Rethink Autism. The parents would also have a consultation from a Board Certified Behavior Analyst to determine if the treatment is being implemented appropriately.
- c. Not all families would be able to implement this program but it can be something to be considered in order to support some families. Other types of video teleconferencing warrant consideration during the Waiver Renewal. Rethink Autism uses Applied Behavior Analysis as the treatment modality which is evidence-based.

VI. Coordination between Insurance and Waiver Benefits

- a. DHS has been collaborating with the Office of the Commissioner of Insurance (OCI), county administrative agencies, and CLTS Waiver providers of treatment services in an effort to coordinate insurance benefits with Waiver funding.
- b. Families need to contact OCI when they are struggling to find reasonable access to providers. Insurers are still trying to build capacity of providers for both intensive and ongoing services. This is causing difficulty for families that may need to travel a few hours to get to the only provider that is in-network. Families may then choose to go out of network which means the family must pay higher deductibles.
- c. DHS hosted five regional autism insurance mandate discussions with both county administrative agencies and intensive in-home providers. During these discussions we were able to discuss issues such as deductibles, co-pays, parental payment limits, and how billing should occur.
- d. DHS is also hosting two intensive in-home provider meetings in May. The purpose is to inform providers of the current insurance mandate, billing during the time insurance covers, and waiver eligibility.
- e. A child that is participating in the CLTS Waiver is required to follow the rules and policies of the Medicaid Home and Community Based Waiver program in order to maintain eligibility. The intensive treatment hours funding by insurance will be considered for the transition to ongoing CLTS Waiver services.
- f. Children that are in the on-going services are struggling with multiple issues.
 - i. Co-morbid diagnosis
 - ii. High Co-pays and deductibles
 - iii. Finding an appropriate provider
- g. The family may have insurance that is from out of state. Insurance is required to cover the mandate if there are at least 25% of those insured reside in WI.

VII. Approval of Minutes

- a. Clarify III. c regarding the intensive hours funding by insurance will be considered for the transition to ongoing CLTS Waiver services
- b. Terri made motion to approve the minutes

- c. Milana 2nd motion
- d. All Approved

VIII. Reviewed Data provided by DHS regarding children participating in the Children's Long-Term Support Waivers for autism services

- a. Currently on wait list: 288
 - i. Next child to receive a slot waited since 08/18/09 or about 9 months
 - ii. Ages on wait list range from 2 years, 3 months to 8 years, 6 months
 - iii. Average age on wait list: 4 years, 9 months
- b. Currently receiving intensive services: 853
 - i. Under age 6: 362
 - ii. Age 6 and up: 491
 - iii. Number who should transition in 2010: 80
 - iv. Average age today: 6 years, 6 months
- c. Currently receiving ongoing services: 1398
 - i. Under age 12: 781
 - ii. Age 12 through 16: 465
 - iii. Age 17 through 21: 152
 - iv. In Family Care counties, will transition to adult in 2010: 69
 - v. In non-Family Care counties, will transition to adult in 2010: 3

IX. Current Trends observed by Council Members

- a. Providers are noticing more children being referred to them as soon as they receive the diagnosis. Families have insurance and don't have to wait for CLTS Waiver funding.
- b. Children that are no longer in the intensive services need additional supports from providers that can meet the needs of the families. It can be difficult for older children to receive the appropriate social cueing and job coaching in order to help them succeed.
- c. The Division of Vocational Rehabilitation has waiting lists and there are mixed messages about the different roles of State Departments. Should the school be funding training or some other agency?
- d. Families struggle to find qualified providers and may hire providers that don't have the qualifications to implement a behavioral treatment plan.

X. Children's Long-Term Care Reform-Julie Bryda

- a. The Children's Long-Term Support Council has been working for a number of years on Children's Redesign effort. In the last year, the Department developed a Request For Proposal (RFP) with the intent of piloting a centralized intake and access to determine eligibility for all long-term support programs for children. COMPASS WISCONSIN-Threshold was developed in Racine County and Walworth County to assist with the demonstration. The demonstration project began on April 19th, 2010.

- XI. Outcome of webcast training-Katie Sepnieski
 - a. The Children's Service Section developed a CLTS Waiver basics web-based training for all new support and service coordinators. The Waiver Basics was completed by DHS staff. The webcasts are overviews of each chapter of the CLTS Home and Community Based Waiver Manual.

- XII. Council Member Updates
 - a. Glen Sallows passed out a handout of a poster session that was co-presented by the Wisconsin Early Autism Project and the University of Wisconsin- Madison at a National conference.

- XIII. The Council adjourned at 2:58 p.m.